Assembly Bill No. 48

CHAPTER 368

An act to amend Section 103885 of, and to amend the heading of Chapter 2 (commencing with Section 103875) of Part 2 of Division 102 of, the Health and Safety Code, relating to health.

[Approved by Governor September 7, 2000. Filed with Secretary of State September 8, 2000.]

LEGISLATIVE COUNSEL'S DIGEST

AB 48, Cedillo. Ken Maddy California Cancer Registry.

Existing law requires the State Department of Health Services to conduct a program of epidemiological assessments of the incidence of cancer. Pursuant to this authority, the department established the California Cancer Registry.

This bill would rename the registry the Ken Maddy California Cancer Registry, and would replace the references to ''tumor'' in these cancer registry provisions with ''cancer.'' The bill would also expand the definition of cancer for these purposes to include primary intracranial and central nervous system tumors occurring in specified sites.

This bill would incorporate additional changes in Section 103885 of the Health and Safety Code, proposed by SB 1596, to be operative only if SB 1596 and this bill are both chaptered and become effective January 1, 2001, and this bill is chaptered last.

The people of the State of California do enact as follows:

SECTION 1. The heading of Chapter 2 (commencing with Section 103875) of Part 2 of Division 102 of the Health and Safety Code is amended to read:

CHAPTER 2. KEN MADDY CALIFORNIA CANCER REGISTRY

SEC. 2. Section 103885 of the Health and Safety Code is amended to read:

103885. (a) The director shall establish a statewide system for the collection of information determining the incidence of cancer, using population-based cancer registries modeled after the Cancer Surveillance Program of Orange County. As of the effective date of this section the director shall begin phasing in the statewide cancer reporting system. By July 1, 1988, all county or regional registries shall be implemented or initiated. By July 1, 1990, the statewide cancer reporting system shall be fully operational. Within 60 days of the

effective date of this section, the director shall submit an implementation and funding schedule to the Legislature.

(b) The department may designate any demographic parts of the state as regional cancer incidence reporting areas and may establish regional cancer registries, with the responsibility and authority to carry out the intent of this section in designated areas. Designated regional registries shall provide, on a timely basis, cancer incidence data as designated by the state department to the department. The department may contract with an agency, including, but not limited to, a health systems agency, single county health department, multicounty health department grouping, or nonprofit professional association, representing a designated cancer reporting region for the purposes of collecting and collating cancer incidence data.

(c) The director shall designate cancer as a disease required to be reported in the state or any demographic parts of the state in which cancer information is collected under this section. All cancers diagnosed or treated in the reporting area shall thereafter be reported to the representative of the department authorized to compile the cancer data, or any individual, agency, or organization designated to cooperate with that representative.

(d) (1) Any hospital or other facility providing therapy to cancer patients within an area designated as a cancer reporting area shall report each case of cancer to the department or the authorized representative of the department in a format prescribed by the department. If the hospital or other facility fails to report in a format prescribed by the department, the department's authorized representative may access the information from the hospital or the facility and report it in the appropriate format. In these cases, the hospital or other health facility shall reimburse the state department or the authorized representative for its cost to access and report the information.

(2) Any physician and surgeon, dentist, podiatrist, or other health care practitioner diagnosing or providing treatment for cancer patients shall report each cancer case to the department or the authorized representative of the department except for those cases directly referred to a treatment facility or those previously admitted to a treatment facility for diagnosis or treatment of that instance of cancer.

(e) Any hospital or other facility that is required to reimburse the department or its authorized representative for the cost to access and report the information pursuant to subdivision (d) shall provide payment to the department or its authorized representative within 60 days of the date this payment is demanded. In the event any hospital or other facility fails to make the payment to the department or its authorized representative within 60 days of the date the payment is demanded, the department or its authorized representative may, at its discretion, assess a late fee not to exceed

$1^1/_2$ percent per month of the outstanding balance. Further, in the event that the department or its authorized representative takes a legal action to recover its costs and any associated fees, and the department or its authorized representative receives a judgment in its favor, the hospital or other facility shall also reimburse the department or its authorized representative for any additional costs it incurred to pursue the legal action. Late fees and payments made to the department by hospitals or other facilities pursuant to this subdivision shall be considered as reimbursements of the additional costs incurred by the department.

(f) All physicians and surgeons, hospitals, outpatient clinics, nursing homes and all other facilities, individuals or agencies providing diagnostic or treatment services to patients with cancer shall grant to the department or the authorized representative access to all records that would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified cancer patient. Willful failure to grant access to those records shall be punishable by a fine of up to five hundred dollars ($500) each day access is refused. Any fines collected pursuant to this subdivision shall be deposited in the General Fund.

(g) All information reported pursuant to this section shall be confidential as provided in Section 100330, except that the department and any regional cancer registry designated by the department shall use the information to determine the sources of malignant neoplasms and evaluate measures designed to eliminate, alleviate, or ameliorate their effect. The department and any regional cancer registry designated by the department may enter into agreements to furnish confidential information to other states' cancer registries, federal cancer control agencies, local health officers, or health researchers for the purposes set forth in this subdivision if those out-of-state registries, agencies, officers, or researchers agree in writing to maintain the confidentiality of the information, and in the case of researchers, if they have obtained the approval of their committee for the protection of human subjects established in accordance with Part 46 (commencing with Section 46.101) of Title 45 of the Code of Federal Regulations.

(h) For the purpose of this section, ''cancer'' means either of the following:

(1) All malignant neoplasms, regardless of the tissue of origin, including malignant lymphoma, Hodgkins disease, and leukemia, but excluding basal cell and squamous cell carcinoma of the skin.

(2) All primary intracranial and central nervous system (CNS) tumors occurring in the following sites, irrespective of histologic type: brain, meninges, spinal cord, caudae equina, cranial nerves and other parts of the CNS, pituitary gland, pineal gland, and craniopharyngeal duct.

(i) Nothing in this section shall preempt the authority of facilities or individuals, providing diagnostic or treatment services to patients with cancer, to maintain their own facility-based cancer registries.

(j) It is the intent of the Legislature that the department, in establishing a system pursuant to this section, maximize the use of available federal funds.

SEC. 3. Section 103885 of the Health and Safety Code is amended to read:

103885. (a) The director shall establish a statewide system for the collection of information determining the incidence of cancer, using population-based cancer registries modeled after the Cancer Surveillance Program of Orange County. As of the effective date of this section, the director shall begin phasing in the statewide cancer reporting system. By July 1, 1988, all county or regional registries shall be implemented or initiated. By July 1, 1990, the statewide cancer reporting system shall be fully operational. Within 60 days of the effective date of this section, the director shall submit an implementation and funding schedule to the Legislature.

(b) The department may designate any demographic parts of the state as regional cancer incidence reporting areas and may establish regional cancer registries, with the responsibility and authority to carry out the intent of this section in designated areas. Designated regional registries shall provide, on a timely basis, cancer incidence data as designated by the state department to the department. The department may contract with an agency, including, but not limited to, a health systems agency, single county health department, multicounty health department grouping, or nonprofit professional association, representing a designated cancer reporting region for the purposes of collecting and collating cancer incidence data.

(c) The director shall designate cancer as a disease required to be reported in the state or any demographic parts of the state in which cancer information is collected under this section. All cancers diagnosed or treated in the reporting area shall thereafter be reported to the representative of the department authorized to compile the cancer data, or any individual, agency, or organization designated to cooperate with that representative.

(d) (1) Any hospital or other facility providing therapy to cancer patients within an area designated as a cancer reporting area shall report each case of cancer to the department or the authorized representative of the department in a format prescribed by the department. If the hospital or other facility fails to report in a format prescribed by the department, the department's authorized representative may access the information from the hospital or the facility and report it in the appropriate format. In these cases, the hospital or other health facility shall reimburse the state department or the authorized representative for its cost to access and report the information.

(2) Any physician and surgeon, dentist, podiatrist, or other health care practitioner diagnosing or providing treatment for cancer patients shall report each cancer case to the department or the authorized representative of the department except for those cases directly referred to a treatment facility or those previously admitted to a treatment facility for diagnosis or treatment of that instance of cancer.

(e) Any hospital or other facility that is required to reimburse the department or its authorized representative for the cost to access and report the information pursuant to subdivision (d) shall provide payment to the department or its authorized representative within 60 days of the date this payment is demanded. In the event any hospital or other facility fails to make the payment to the department or its authorized representative within 60 days of the date the payment is demanded, the department or its authorized representative may, at its discretion, assess a late fee not to exceed $1^1/_2$ percent per month of the outstanding balance. Further, in the event that the department or its authorized representative takes a legal action to recover its costs and any associated fees, and the department or its authorized representative receives a judgment in its favor, the hospital or other facility shall also reimburse the department or its authorized representative for any additional costs it incurred to pursue the legal action. Late fees and payments made to the department by hospitals or other facilities pursuant to this subdivision shall be considered as reimbursements of the additional costs incurred by the department.

(f) All physicians and surgeons, hospitals, outpatient clinics, nursing homes and all other facilities, individuals or agencies providing diagnostic or treatment services to patients with cancer shall grant to the department or the authorized representative access to all records that would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified cancer patient. Willful failure to grant access to those records shall be punishable by a fine of up to five hundred dollars ($500) each day access is refused. Any fines collected pursuant to this subdivision shall be deposited in the General Fund.

(g) (1) All data including, but not limited to, medical and pathology records, records of health status, interviews, questionnaires, reports, statements, notes, and memoranda collected pursuant to this section shall be confidential. Access shall be limited to the department and any regional registry designated by the department except as otherwise provided in this subdivision.

(2) The department and any regional cancer registry designated by the department may enter into agreements to furnish confidential data to other states' cancer registries, federal cancer control agencies, local health officers, or health researchers for the purposes of determining the sources of malignant neoplasms and evaluating

measures designed to eliminate, alleviate, or ameliorate their effect. Before confidential data are disclosed to those out-of-state registries, agencies, officers, or researchers, the requesting entity shall agree in writing to maintain the confidentiality of the information, and, in the case of researchers, shall do both of the following:

(A) Obtain approval of their committee for the protection of human subjects established in accordance with Part 46 (commencing with Section 46.101) of Title 45 of the Code of Federal Regulations.

(B) Provide documentation to the department that demonstrates to the department's satisfaction that the entity has established the procedures and ability to maintain the confidentiality of the information.

(3) Confidential data may be disclosed to other local, state, or federal public health or environmental agencies, or to collaborating medical researchers, when the confidential data are necessary to carry out the duties of the agency or researcher in the investigation, control, or surveillance of disease, as determined by the department.

(4) Any disclosure authorized by this section shall include only the information necessary for the stated purpose of the requested disclosure and shall be made only upon written agreement that the information will be kept confidential and will not be further disclosed without written authorization of the department.

(5) The furnishing of confidential data to the department or its authorized representative or to any other cooperating individual, agency, or organization in any study in accordance with this subdivision shall not expose any person, agency, or entity furnishing data to liability and shall not be considered to be the violation of any privileged or confidential relationship.

(6) (A) There shall be a rebuttable presumption that the necessity for preserving the confidentiality of the data outweighs the necessity for disclosure. The confidential data may only be subject to discovery or subpoena if the party seeking the disclosure rebuts the presumption. This presumption may only be overcome if the court finds that the disclosure of the information will serve to protect public health or safety.

(B) If the court finds that the presumption has been rebutted and the confidential data is subject to discovery or subpoena, certain confidential information shall be redacted. This information includes personal names, addresses, telephone numbers, social security numbers, personal identification numbers, insurance policy numbers, specific places of employment and education, any other data that identifies or accesses the participant or any friends, employers, or associates of the participant, and any other data the court deems appropriate. The party requesting the data shall be responsible for all costs associated with the production of the data, including costs attributable to any time required to redact the

confidential information. The party requesting the data shall demonstrate the ability to ensure data security and confidentiality.

(7) (A) Notwithstanding any other provision of law, any person who violates this subdivision shall be subject to civil and criminal penalties and other actions in accordance with Section 56.36 of the Civil Code.

(B) Any person who intentionally discloses confidential data to any third party, except as authorized in this subdivision, may be denied further access to confidential data maintained by the department.

(8) Nothing in this subdivision shall prohibit the publication by the department of reports and statistical compilations relating to the causes of malignant neoplasms or measures to eliminate, alleviate, or ameliorate the effect of malignant neoplasms that do not identify individual cases and sources of information or religious affiliations.

(h) For the purpose of this section, ''cancer'' means either of the following:

(1) All malignant neoplasms, regardless of the tissue of origin, including malignant lymphoma, Hodgkins disease, and leukemia, but excluding basal cell and squamous cell carcinoma of the skin.

(2) All primary intracranial and central nervous system (CNS) tumors occurring in the following sites, irrespective of histologic type: brain, meninges, spinal cord, caudae equina, cranial nerves and other parts of the CNS, pituitary gland, pineal gland, and craniopharyngeal duct.

(i) Nothing in this section shall preempt the authority of facilities or individuals, providing diagnostic or treatment services to patients with cancer, to maintain their own facility-based cancer registries.

(j) It is the intent of the Legislature that the department, in establishing a system pursuant to this section, maximize the use of available federal funds.

SEC. 4. Section 3 of this bill incorporates amendments to Section 103885 of the Health and Safety Code proposed by both this bill and SB 1596. It shall only become operative if (1) both bills are enacted and become effective on or before January 1, 2001, (2) each bill amends Section 103885 of the Health and Safety Code, and (3) this bill is enacted after SB 1596, in which case Section 2 of this bill shall not become operative.

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